

**The effects of a digital memory book
on the quality and quantity of conversations in adults
with mild to moderate dementia**

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THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN
ADULTS WITH MILD TO MODERATE DEMENTIA

Table of Contents

List of abbreviations.....	3
List of figures	4
List of Tables.....	5
Acknowledgements.....	6
Abstract.....	7
1. Introduction.....	9
1.1. Dementia.....	9
1.1.1. Alzheimer’s disease.....	11
1.2. Dementia and Communication.....	12
1.3. Dementia and Reminiscent Therapy.....	15
1.4. Dementia and ACC.....	17
1.5. Dementia and Tablet Computers.....	20
1.6. Research Aim.....	21
2. Method.....	22
2.1. Research design.....	22
2.2. Ethical Approval	22
2.3. Participants.....	23
2.3.1. Recruitment.....	23
2.3.2. Inclusionary and Exclusionary Criteria.....	23
2.3.3. Participant Description.....	24
2.4. Setting.....	28
2.5. Stimuli.....	28
2.6. Procedures.....	30
2.6.1. Initial Screening Procedures.....	31
2.6.2. Baseline, Treatment, and Follow-up Phases.....	31
2.8. Data Analysis.....	35
3. Results.....	39

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

3.1. Effects of a digital memory book on the quantity and quality of conversations of adults with a mild to moderate dementia.....	39
3.1.1. Participant 1.....	39
3.1.2. Participant 2.....	42
3.1.3. Participant 3.....	44
3.1.4. Participant 4.....	47
3.2. Effects of the digital memory book on total-on-topic statements during conversations with the family member participant.....	50
3.3. Participants' non-targeted communicative behaviours.....	52
3.4. Communication Partner Utterances.....	55
3.5. Summary of results.....	57
4. Discussion.....	58
4.1. Effects of the digital memory book on the quality and quantity of conversations.	58
4.2. Limitations.....	61
5. Conclusion.....	63
References.....	64
Appendices.....	68
Appendix A: Information Form for Participant.....	68
Appendix B: Consent Form for Participant.....	70
Appendix C: Consent Form for Family Member.....	73

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN
ADULTS WITH MILD TO MODERATE DEMENTIA

List of Abbreviations

AAC	Augmentative and Alternative Communication
ACE-R	Addenbrooke's Cognitive Examination - Revised
ASHA	American Speech-Language-Hearing Association
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders (5 th edition)
FLCI	Functional Linguistic Communication Inventory
MMSE	Mini-Mental State Examination
SBU	The Swedish Council on Technology Assessment in Health Care
SLT	Speech and Language Therapist

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN
ADULTS WITH MILD TO MODERATE DEMENTIA

List of Figures

Figure 1:	Number of on-topic statements per 5-minute conversation – Participant 1.....	41
Figure 2:	Number of on-topic statements per 5-minute conversation – Participant 2.....	43
Figure 3:	Number of on-topic statements per 5-minute conversation – Participant 3.....	46
Figure 4:	Number of on-topic statements per 5-minute conversation – Participant 4.....	49
Figure 5:	Total of on-topic utterances in one baseline and one follow-up session conducted by family member.....	51
Figure 6:	Mean frequency of non-targeted communicative behaviours.....	54
Figure 7:	Mean Frequency of partner and non-partner Utterances in baseline and treatment.....	56

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

List of Tables

Table 1:	Participant characteristics.....	25
Table 2:	Participant performance on ACE-R with MMSE score.....	26
Table 3:	Participant performance on the FLCL.....	26
Table 4:	Characteristics of family member participants.....	27
Table 5:	Sample digital memory book stimuli and prompts.....	29
Table 6:	Definitions of conversational codes.....	36

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THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

Abstract

Background: Research has demonstrated that adults with a moderate dementia can benefit from the introduction of a memory book to improve the quality of their conversational content. However, previous investigations in the area have focussed on low-tech alternative and augmentative communication aids. Few studies have investigated how digital media can be incorporated into therapy when working with people living with dementia. The present study addresses this gap in the literature by investigating the effects of a digital memory book on the quality and quantity of conversations in adults with mild to moderate dementia.

Method: A single-subject multiple baseline design across behaviours with replication across four participants was used in this investigation. Four English speaking adults with a mild to moderate dementia and four of their family members participated in the study. The researcher developed a digital memory book using the *Pictello™* application on an Apple iPad with the help of the participant and their family/whānau. Photos and statements were chosen in relation to these three conversational topics: Daily Life, Family, and Myself. During baseline and treatment sessions, the researcher met with each participant to conduct and record a five-minute conversation based on the three conversational topics. During treatment sessions, the researcher used the digital memory book to establish the effect of the memory book on the participants' conversational utterances. Each conversation was transcribed verbatim by the researcher and analysed and coded for Memory Book Statements, Novel On-Topic Statements, Ambiguous Utterances, Unintelligible Utterances, Perseverative Utterances, Error Statements, Other Utterances, Partner Prompts, Partner Statements, Partner Questions, and Partner Other statements. A research assistant independently transcribed 20% of the transcripts and coded 20% of the conversations to establish the inter-observer agreement for the transcription and coding.

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

Results: Visual analysis of the total-on-topic statements revealed a lack of evidence of a clear difference between the baseline and treatment phases across all the behaviours for each of the four participants. All four participants increased their total-on-topic statements with family members during an initial baseline session without the digital memory book to a follow-up session involving the digital memory book.

Conclusion: Although the use of a digital memory book did not improve the quality and quantity of conversations in adults with mild to moderate dementia during conversations with the researcher, further research in the area is warranted. Future studies could focus on individuals with moderate or more severe dementia and individuals who are familiar with using digital media in their daily lives. Research could also focus more on the use of digital memory books during conversations with family members.

1. Introduction

It is expected that there will be a significant increase in the number of adults with dementia in New Zealand as the proportion of older people in the population grows (Alzheimer's New Zealand Incorporated, 2011; Ministry of Health, 2011). Declines in memory and other cognitive functions which characterise dementia have an unavoidable effect on a person with dementia's ability to participate in conversation (ASHA, 2005a). However, many adults with dementia have their own, or access to, computers and other electronic and digital items which can be used to enhance memory and communication. One benefit of mobile technology, such as Smartphones and portable personal computers, is that they are generally more affordable and smaller than traditional augmentative and alternative communication (AAC) devices. Furthermore, tablets, such as the *Apple iPad™*, are commonly used in the general population and therefore do not possess the same social stigma as many other AAC aids. This thesis describes a single-subject multiple baseline study which investigated the effect of using an *Apple iPad™* (iPad 2, iOS version 8.0.2) with an application, *Pictello™* (AssistiveWare, 2012; version 3.0), as a digital memory book, on the quality and quantity of conversations in adults with mild to moderate dementia.

1.1. Dementia

Dementia, an acquired neurological disorder, is characterised by a global decline in a person's cognitive functioning which, largely associated with memory, can also affect a person's language, personality, and perception (Alzheimer's New Zealand, 2008; Gustafson, 1996; Macoir & Turgeon, 2006; Ministry of Health, 2011). As well as impaired memory, at least one of the following symptoms is also required for a diagnosis of dementia: spatial disorientation, language disturbance, reduced ability to perform activities of daily living independently, or personality changes resulting in

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

impaired judgement, emotional bluntness, aggressiveness, or reduced insight (The Swedish Council on Technology Assessment in Health Care [SBU], 2008). Psychiatric features, such as anxiety, depression, suspiciousness, or delusions, can also be present in individuals with dementia (Gustafson, 1996). According to the *Diagnostic and Statistical Manual of Mental Disorders, 5th ed*, (DSM-V), to be diagnosed with dementia (or as now referred to in the DSM-V, a *Major Neurocognitive Disorder*), one must present with one or more acquired impairments in one of the cognitive domains which are significant enough to impair a person's functioning, and result in loss of independence, in a social or occupational context (American Psychiatric Association, 2013a). Cognitive domains include memory (amnesia), language (aphasia), execution of purposeful movement (apraxia), recognition/familiarity (agnosia), visuospatial function (topographical disorientation), or self-control/management (executive functions impairment) (American Psychiatric Association, 2013).

Risk factors associated with dementia include age, family history and genetic factors, gender, cardiovascular risk factors, and stroke-related and atherogenic causes. The likelihood of developing a dementia increases with age from approximately 1 in 1000 for people under the age of 65, to 1 in 100 for people in their 60s, and to 1 in 4 for people 85 years and older (Alzheimer's New Zealand, 2008; Fried-Oken, et al., 2012). While Alzheimer's disease appears to be more prevalent in women than men over 80 years, men have been reported to be at a higher risk of vascular dementia than women (Alzheimer's New Zealand, 2008). It has been hypothesised that exposure to certain environments in the workplace may place a person at higher risk of developing a dementia later in life (Alzheimer's New Zealand, 2008); however, further research on the relationship between environmental factors and dementia is needed. New Zealand Māori have also been reported to have higher rates of risk factors for developing dementia and other age-related conditions such as depression, cardiovascular illnesses, head trauma, and substance abuse disorders than their non-Māori peers (Ministry of Health, 2011).

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

Dementia is typically a non-reversible deterioration in cognitive function; however, some dementias can be associated with potentially reversible conditions such as infection, depression, thyroid disease, normal pressure hydrocephalus, or drug toxicity (ASHA, 2005a). The most common cause of dementia is Alzheimer's disease which accounts for approximately 50-70% of all dementias (ASHA, 2005a; Alzheimer's New Zealand, 2008; Ministry of Health, 2011). Other types of dementia include vascular dementia, fronto-temporal dementia, dementia with lewy bodies, and dementias related to Parkinson's disease, Huntington's disease or HIV. Subtypes of dementia are based on common characteristics, such as typical symptom presentation and progression, and psychiatric and behavioural features (American Psychiatric Association, 1994).

1.1.1. *Alzheimer's Disease*

Alzheimer's disease, the most common type of dementia, has a recognised neuropathology in which the disease produces cortical lesions associated with senile plaques and neurofibrillary tangles (Bayles, 2003; Macoir & Turgeon, 2006; Perl, 2010; SBU, 2008). In most cases of Alzheimer's disease, there is also a degree of cerebral cortical atrophy, primarily associated with the fronto-temporal cortex, dilation of the lateral ventricles, and significant atrophy of the hippocampus (Perl, 2010). Impairment in the frontal cortex in Alzheimer's disease reduces a person's working memory by decreasing attention, diminishing span capacity, and impairing search and retrieval functions which affects a person's language comprehension and expression (Bayles, 2003). As the disease includes areas in the temporo-parietal cortex, semantic memory becomes disrupted with both of these memory systems becoming more impaired as the disease progresses (Bayles, 2003; Macoir & Turgeon, 2006).

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

1.2 *Dementia and Communication*

Deficits in language have been demonstrated to be typically more prominent approximately two to three years from the onset of the dementia (Macoir & Turgeon, 2006). As the disease progresses, impairments in memory, language, and judgement become more severe, and difficulties in activities of daily living become increasingly evident. Deterioration in semantic memory, or access to the words needed to formulate a specific message, is an early symptom of dementia that can have a negative effect on conversation (Fried-Oken et al, 2012). Semantic memory stores information related to objects, concepts, words, and their meanings. Deficits in semantic memory can lead to difficulties in word-finding, word comprehension, naming, and verbal description (Macoir & Turgeon, 2006). Therefore declines in memory and other cognitive function which characterise dementia have an unavoidable effect on a person with dementia's ability to participate in conversation (ASHA, 2005a). Those in the later-stage of the disease may show a reduction in language and decreased recognition of family members and of self. They may also experience delusions and hallucinations, and demonstrate repetitive and/or behaviours uncharacteristic of the person prior to the progression of the disease.

Bayles, Tomoeda, and Trosset (1992), explored linguistic communication in 152 adults with Alzheimer's disease and compared the results with 60 individuals without neurological impairments to document the effects of Alzheimer's disease on linguistic communication function and developed a communication profile for each stage of the Global Deterioration Scale (GDS), developed by Reisberg et al in 1982 (as cited in Reisberg, 1990). The GDS has seven stages: subjectively and objectively normal (GDS stages 1 and 2), mild cognitive impairment (GDS stage 3), early dementia (GDS stage 4), moderate dementia (GDS stage 5), moderately severe dementia (GDS stage 6), and severe dementia (GDS stage 7) (Bayles et al, 1992; SBU 2008). Bayles et al (1992) described people rated at stage 5 of the GDS as requiring assistance to remain independent, being disoriented to time

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

and place, but retaining knowledge of facts about self. This population also showed the most variation in presentation in linguistic communication function, although performance of oral reading was similar to scores of people without Alzheimer's disease. Based on the linguistic communication profile developed by Bayles et al (1992), people rated with a stage 5 on the GDS dementia scale obtained scores of greater than, or equal to, 50% of those of normal controls on auditory comprehension, writing to dictation, reading comprehension, and pantomime expression. Tasks identified as being the most difficult included providing names of objects from a similar category, and naming a category to which a stimulus belongs.

The most well-known symptom of dementia is impairment in a person's declarative memory. In Alzheimer's disease, as well as deterioration in memory, impairment in the frontal cortex can affect a person's comprehension and expression of language (Bayles, 2003). During the early stages of Alzheimer's disease, people may experience a mild short-term memory loss in addition to a mild forgetfulness for names and objects, mild word finding difficulties, and difficulties in abstract reasoning, attention, language, and spatial cognition (Bourgeois, 2002). Decline in a person's cognitive and language function can then lead to confused, repetitive verbalizations, and reduced cohesion in communication (Appell, Kertesz, & Fisherman, 1982; Kempler & Goral, 2008; Ripich & Terrell, 1988). This decline in an individual with dementia's communicative performance is not the result of a loss of linguistic or conceptual knowledge, but is instead a consequence of difficulty in storing, retrieving, and manipulating linguistic information (Bayles, 2003). Frontal lobe pathology in Alzheimer's disease weakens working memory by reducing span capacity, limiting a person's attention, and disrupting search and retrieval functions. Because language comprehension and expression rely on the integrity of these functions, individuals with Alzheimer's disease perform poorer than individuals without Alzheimer's disease on a number of various communication tasks (Bayles, 2003). Given that people with Alzheimer's disease have difficulties with making and storing

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

new memories, their ability to participate in, and contribute to conversation becomes impaired (Gowans, et al., 2004; Alm, et al., 2004).

Other communication difficulties present in this population include verbal perseveration, specifically repetition of the same idea or question, impairment in turn-taking and topic maintenance, diminished vocabulary, disordered oral and written discourse, as well as impaired reading comprehension (Bourgeois, 1991). In the later stage of dementia, individuals may present with mutism, echolalia, and unusual nonsensical utterances (Bourgeois, 1991). Bayles, Tomoeda, and Trosset (1992) found that dramatic declines in functional communication are not caused by normal aging, but are part of a dementing illness. The study by Bayles and colleagues allowed the researchers to develop a profile of linguistic communication abilities of individuals diagnosed with Alzheimer's disease by the stage of the disease, as correlated to the Global Deterioration Scale (GDS), allowing clinicians to predict the progression of the disease in relation to communication. This study demonstrated that individuals with a GDS stage-5 rating of Alzheimer's disease (moderate-severe cognitive decline) performed close to normal in ability to read aloud. Auditory comprehension and reading comprehension were also both demonstrated to be relatively preserved at stage-5 of the GDS.

People presenting with dementia-related communication disorders have been identified as the Speech-Language Therapist (SLT) profession's fastest growing clinical population (American Speech-Language-Hearing Association [ASHA] 2005a). This does not include SLT involvement with older people diagnosed with dementia who are referred for assessment and management of dysphagia. In New Zealand, the number of people diagnosed with dementia is expected to increase from 1.1% of the population (48,182) in 2011, to 2.6% of the population (approximately 147,359 people) by 2050 (Alzheimer's New Zealand Incorporated, 2011). A cost benefit analysis conducted in

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

2008 demonstrated considerable financial benefit in supporting people living with dementia to continue living at home, rather than being placed into residential care (Alzheimer's New Zealand Incorporated, 2008). A number of factors are involved when families make the decision they are no longer able to support their family member living with dementia at home and a move into residential care is made.

SLTs can assist individuals with dementia and their families and caregivers by providing facilitative strategies that encourage them to maintain meaningful communication (Bourgeois, 2002). During the early stages of the disease, individuals with Alzheimer's disease may take a central role in their own therapy for memory rehabilitation, learning strategies and adopting the use of external aids to enhance memory and compensate for impairments. As the disease progresses, family, whānau, and caregivers can become more involved in efforts to support their memory as well as to target dementia-related behaviours such as orientation, repetitive questioning, and prompting through activities of daily living. The overall aim for clinicians using AAC as an intervention method for dementia is to maximise the person with dementia's communicative and memory functioning.

1.3. Dementia and Reminiscent Therapy

One approach utilised in SLT, reminiscent therapy, involves the use of physical prompts such as photo-albums, music, memorabilia, videos, and themed environments to encourage the person with dementia to recall the past and engage in conversation (Gowans et al, 2004; Lazar et al, 2014). It involves activation of multiple cognitive systems, including attention, semantic and episodic memory, and language (Kim et al, 2006). Reminiscent therapy is based on the assertion that people with dementia retain their long-term memory, and that when provided the appropriate stimulus, they will recall personal experiences from their past to engage in meaningful activities or conversations of interest (Gowans et al, 2004; Kim, et al., 2006). Autobiographical memory can be

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

important in contributing to a person's ability to maintain meaning and access to specific words, which can in turn, can enhance their conversations (Bourgeois, 2002). People with an early to moderate dementia have a greater preservation of long-term compared to recent autobiographical memories and therefore, it is assumed, that talking about previous life events would provide enhanced communicative interactions for these individuals (Kim et al, 2006). It is recommended that reminiscence therapy activities reflect a person with dementia's past experiences, interests, and hobbies, whilst maintaining and promoting their maximum functional potential (Leng et al, 2013). Reminiscence therapy has been demonstrated to have positive effects on individuals with dementia with positive changes in self-esteem and affect, increase in communication skills, an association with increased life satisfaction and reduction in depression (Kim et al, 2006). It has also been shown to improve function by reducing the demands on impaired cognition and make the most of reserved abilities (Kim et al, 2006). Reminiscence therapy can also be beneficial for family members and staff in residential care settings by providing a new way for them to interact and converse with the person with dementia (Lazar et al., 2014). Alm and colleagues (2004) suggested that a reminiscence-type experience based on a computer, utilising multimedia technologies, may provide a more enriching and meaningful activity for people who have difficulty in engaging in spontaneous interactions. They indicated that reminiscence therapy, which makes use of a range of differing separate media, can be time consuming in organising and searching for specific stimuli; and that by employing a computer system to integrate all of the different stimulus sets into one framework would save time and provide seamless inclusion of text, photographs, graphics, music, and videos (Alm et al, 2004). One of the pilot studies conducted by Alm et al (2004) explored which aspects of multimedia would be useful to include in a digital reminiscence scrapbook; and the best way to present the finished product. Prototypes were demonstrated for people with dementia and staff members at a day programme run by an Alzheimer's group in Scotland. Staff members indicated a preference for a simulated scrapbook presentation; however the preference for the people with dementia was a simple screen presentation. Staff members and individuals with dementia both preferred to have

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

the material to be organised by subject, rather than by medium. Videos elicited a strong response only if the person with dementia viewing the video had specific personal memories triggered by the video; whereas photographs and songs were observed to be more greatly appreciated (Alm et al, 2004). One general finding from the pilot was that a multimedia presentation generated both interest and motivation among the people with dementia and highlighted a need to explore further ways in which technology can support conversation for adults with dementia (Alm et al, 2004). Computer Interactive Reminiscence and Conversation Aid (CIRCA) (Gowans et al, 2004) is another example of a multimedia approach involving reminiscence therapy. CIRCA incorporates a touch-screen interface to stimulate long-term memory, enhance verbal and non-verbal communication, (Lazar et al, 2014).

Although reminiscence therapy would typically involve promoting pleasant and enjoyable memories, it can also be used with memories which elicit feelings of sadness for therapeutic or cathartic purposes (Lazar et al; 2014) Using external aids, such as a memory book, utilises a person with dementia's spared skills and automatic memory processes (Bourgeois, 1991; Fried-Oken et al, 2012). An advantage of reminiscence therapy is that it is appropriate for people with varying cognitive ability as a way to maintain relationships with family (Lazar et al, 2014). Benefits of reminiscence therapy also include reducing social isolation and promoting self-worth, while being an activity of interest to both the person with dementia and their conversation partner (Lazar et al, 2014).

1.4. *Dementia and AAC*

AAC is described as "set of procedures and processes designed to improve (temporarily or permanently), the communication skills of individuals, with little or no functional means of communication" (TalkLink New Zealand, 2015). AAC devices and aids are used by individuals with

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

communication impairment to express their thoughts, needs and wants; as well as to support and enhance conversation by supplementing or replacing speech (Murphy & Cameron, 2008; TalkLink, 2015). While acceptance and use of high-tech AAC in neurodegenerative diseases, such as motor neuron disease, and acquired communication impairments following stroke or traumatic brain injury, have increased; further research is required to identify the role of AAC with individuals with disorders such as dementia (Beukelman, Fager, Ball, & Dietz, 2007). As technology advances, electronic devices are becoming more accessible and applications to support communication available for everyday users to download. Access to communication outside traditional face-to-face interaction is also made available through the use of Smartphones, personal computers and tablets, and the internet. Benefits of using mobile technology include generally being smaller and cheaper than traditional AAC devices, an increased awareness and social acceptance of mobile devices used as AAC, and access to mainstream Smartphone applications (such as text messaging, browsing the internet, and GPS tracking) (McNaughton & Light, 2013). Another advantage of the digital age is the social acceptance of personal tablets, such as the iPad, reducing the stigma which is sometimes associated with using an AAC device (McNaughton & Light, 2012; McNaughton & Light, 2013).

The role of AAC in dementia is different from the role it often plays for individuals with other acquired neurological conditions. Because individuals with dementia may not have difficulty with their speech, they may not require AAC as an expressive communication mode for speech output.. Instead, AAC use in dementia can be used to support memory, as well as to target dementia-related behaviours such as repetitive questioning. The overall aim for clinicians using AAC as an intervention method for dementia is to maximise the person with dementia's communicative and memory functioning in order to maintain, or increase, activities, participation/engagement, and quality of life for the person with dementia across the disease progression (Beukelman, 2007). Interventions may also be used to decrease stress on the person with dementia's whānau/family and caregivers

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

(Beukelman et al, 2007).

Studies involving the use of AAC in dementia range from using external memory cues to the use of memory wallets to promote quality conversation (Beukelman et al, 2007; Bourgeois, 1990; Bourgeois, 1991; Bourgeois, 1993; Bourgeois, Dijkstra, Burgio, & Allen-Burge, 2001; Bourgeois, Fried-Oken, & Rowland, 2010; Chang & Bourgeois, 2012; Fried-Oken, et al., 2012; Murphy, Gray, & Cox, 2007). One investigation completed by Bourgeois (1990) examined the effect of a prosthetic memory aid on the quality and quantity of conversation in eight individuals with moderate dementia. The study found that the introduction of a memory wallet, a low-tech AAC aid comprised of factual statements and photographs related to the participant's life and daily activities, was effective in increasing the overall average number of statements from two to three statements per topic without the memory wallet, to 12-15 statements with the memory wallet. The participants were able to learn to use the memory wallet when having conversations with familiar conversational partners. In a subsequent study in a residential care facility, Bourgeois (1993) found an improvement in turn taking and mutual prompting when two nursing home residents with moderate-severe dementia used memory wallets in conversation with each other (Bourgeois, 1993). The use of the memory wallets was also found to improve the participants' quality and quantity of conversation by increasing their use of factual statements and decreasing the occurrence of non-functional speech.

Another study conducted by Bourgeois (1993) examined the effects of modifying the memory wallet training provided to the participants with dementia. This investigation found that memory wallets could have a positive effect on conversation for adults living with dementia with little or no training.

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

A subsequent study completed by Chang and Bourgeois (2012) evaluated the effects of memory wallets on the conversations of three Chinese speaking adults with dementia. The researchers found that the introduction of the memory wallet had a positive effect on communication by increasing total on-topic statements and reducing ambiguous, unintelligible, erroneous, and off-topic utterances for the participants with dementia.

In addition to these studies, Maclagan and Grant (2011) examined the effect of memory books in adults with dementia in residential care settings when used by caregivers to facilitate conversations about the person with dementia's life history. The researchers found that memory books containing photographs and supporting statements provided a framework to support conversation for a person with dementia with their caregiver and resulted in an increase in novel statements, and decrease in off-topic statements. The authors suggested, however, that training was necessary for caregivers to utilise the person with dementia's memory book, and that providing a memory book to the person with dementia was not sufficient for improving life story conversations (Maclagan & Grant, 2011).

1.5. *Dementia and Tablet Computers*

Personal tablet computers have become increasingly popular among the general public due to their perceived ease of accessibility via an intuitive touch-screen interface. With a touch-screen tablet, external controllers, such as a mouse or external keyboard, are eliminated. Navigation is intuitive and corresponds to real life actions; where the user swipes their finger to scroll the page and taps on an icon to open and activate an app (Lim, Wallace, Luszcz, & Renolds, 2013). Lim et al (2013) identified an advantage of introducing iPads to adults living with dementia, in that they were engaging for the person with dementia, and may provide an opportunity for respite for the

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

caregiver. Lim and colleagues (2013) conducted a trial of using iPads with older adults living with dementia. No support or training was provided to the participants with dementia and as a result, reactions to the iPad by participants were diverse, with approximately half of the participants were able to engage with the iPad independently.

1.6. *Research Aim*

Previous studies investigating external memory aids and memory books as an approach to target cognitive communication impairment secondary to dementia have focussed on low-tech AAC aids. Few studies have looked at using digital media with people with dementia (Lim et al, 2013; Leng et al, 2013; Lazar et al, 2014). We know from previous research (Bourgeois, 1990; Bourgeois 1992; Bourgeois, 1993; Chang, & Bourgeois, 2012; Fried-Oken et al, 2012), that adults with a moderate dementia can benefit from introduction of a memory book to improve the quality of their conversational content. Therefore, the overall aim of this research was to investigate the effects of a digital memory book on the quality and quantity of conversations in adults with mild to moderate dementia. The specific hypothesis of this study was that the use of a digital Memory Book will facilitate conversation with individuals with a mild to moderate dementia by increasing factual on-topic statements made by the participants.

2. Method

2.1. *Research Design*

A single-subject multiple baseline design across behaviours with replication across four participants (McReynolds & Kearns, 1983) was chosen to evaluate the effects of a digital memory book (the independent variable) on total on-topic utterances during conversations (the dependent variable). The study was based on the method used in previous investigations involving the use of low-technology memory wallets/books (Bourgeois, 1990; Bourgeois 1992; Bourgeois, 1993; Chang, & Bourgeois, 2012). Single-subject experimental designs are often suitable for initial treatment studies involving SLT's because they allow participants to act as their own controls (McReynolds & Kearns, 1983). A multiple baseline across behaviours experimental design is often appropriate in SLT studies because no withdrawal or reversal of treatment is required (Schiavetti, Metz, & Orlikoff, 2011).

2.2. *Ethical Approval*

The study was approved by the University of Canterbury Human Ethics Committee and the Human and Disability Ethics Committee.

Although this study was not designed to specifically target the Māori population, the number of New Zealand Māori living with dementia is anticipated to increase with our aging population (Ministry of Health, 2011). Māori have also been reported to have higher rates of risk factors for dementia (Ministry of Health, 2011) and therefore it was a possibility that a participant may identify as Māori. The Treaty of Waitangi was acknowledged throughout the study, and it was determined that should a participant identify as Māori, a kaumātua (māori elder) would have been approached to ensure correct tikanga (māori protocol) and tautoko (support) were available and in place.

2.3. *Participants*

Four adults diagnosed with dementia and four family members (one relative for each participant with dementia) participated in this study.

2.3.1 *Recruitment*

Participants with dementia and their family members were recruited through Alzheimer's Canterbury. Research information sheets were sent to prospective participants (see appendix A) who met the inclusionary criteria. The prospective participants were invited to contact the researcher if they were interested in participating in the investigation. The researcher then met with interested participants to explain and answer questions about the investigation, prior to obtaining their written consent to participate in the study.

2.3.2 *Inclusionary and Exclusionary Criteria*

Inclusionary criteria for the participants with dementia were that they: had been diagnosed with dementia by a physician, were 18 years or older, spoke English, lived at home with at least one other family member, were able to hear adequately for one-on-one conversation as judged by the researcher, had passed a spaced-retrieval screening assessment, could use a swipe action to turn the page on an Apple iPad™ independently, and had a family member who was willing to participate in the study. Exclusionary criteria for the participants with dementia were: presence of comorbid neurologic, communication, and/or psychiatric disorders and presence of severe visual impairment or blindness. To be included in this study, family member participants had to be a frequent (at least daily) conversational partner of the participant with dementia, as indicated by self-report; be 18 years or older, speak English, be able to hear adequately for one-on-one conversation as judged by

the researcher.

2.3.3 Participant Description

Four adults with dementia, one female and three males aged 61 to 88 years old, participated in the study. Each of these participants resided at home with at least one other family member in Christchurch, New Zealand. The participants' family members identified the type of dementia that their relative had. Table 1 provides demographical information about the participants with dementia. Tables 2 and 3 provide individual results in the *Addenbrooke's Cognitive Examination – Revised (ACE-R)* (Moshi et al., 2006) and the *Functional Linguistic Communication Inventory* (Bayles & Tomoeda, 1995). The ACE-R contains an embedded *Mini Mental State Examination (MMSE)* score.

Four family member participants, three females and one male aged between 54 and 73 years, participated in the study. Family members of participants 1, 3 and 4 were the primary caregiver for the participant with dementia. Participant 2's family member was a secondary caregiver who lived with the participant and their primary caregiver (spouse). Table 4 provides descriptive information about the family member participants.

Table 1. Participant characteristics

Participant	Diagnosis	Sex	Age	Ethnicity	Highest Level of Education	FLCI Rating	ACE-R	Residence
1	Vascular Dementia	M	77	NZ European	Intermediate	Mild-moderate	71	Home w/ wife
2	Dementia of Alzheimer's Type	M	88	NZ European	Bachelor's degree	Moderate	26	Home w/ wife, daughter, and son-in-law
3	Dementia of Alzheimer's Type	F	72	NZ European	High School Certificate	Moderate	42	Home w/ husband
4	Dementia of Alzheimer's Type	M	61	NZ European	Other - Qualified Tradesperson	Mild- moderate	58	Home w/ wife

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN
ADULTS WITH MILD TO MODERATE DEMENTIA

Table 2. Participant Performance on *ACE-R* with *MMSE* Score

	Participant	1	2	3	4
Attention and Orientation	/18	13	6	15	11
Memory	/26	15	9	2	10
Fluency	/14	6	0	3	7
Language	/26	22	7	9	19
Visuospatial	/16	15	4	13	11
MMSE	/30	23	12	20	18
ACE-R	/100	71	26	42	58

Table 3. Participant Performance on the *FLCI*

		1	2	3	4
Greeting and Naming	/15	12	8	9	15
Answering Questions	/12	8	10	10	12
Writing	/11	7	0	2	6
Comprehension of Signs & Object to Picture Matching	/6	6	6	6	5
Word Reading	/18	17	16	16	18
Comprehension					
Reminiscing	/6	6	6	5	6
Following Commands	/2	2	2	2	1
Pantomime	/9	9	7	8	5
Gesture	/4	4	4	4	4
Conversation	/4	4	4	3	4
TOTAL	/87	75	63	65	76
RATING		Mild-	Moderate	Moderate	Mild-
		moderate			moderate
Mild: 82-87, Moderate: 71-63, Moderately Severe: 45 -27, Severe: 21-5, Very Severe: 0					

Table 4. Characteristics of the Family Member Participants

Participant	Relationship to Participant with Dementia	Sex	Age	Ethnicity	Highest Level of Education
1	Spouse	F	71	NZ European	High School Certificate
2	Daughter	F	61	NZ European	Bachelor's degree
3	Spouse	M	73	NZ European	High School Certificate
4	Spouse	F	54	NZ European	High School Certificate

2.4. *Setting*

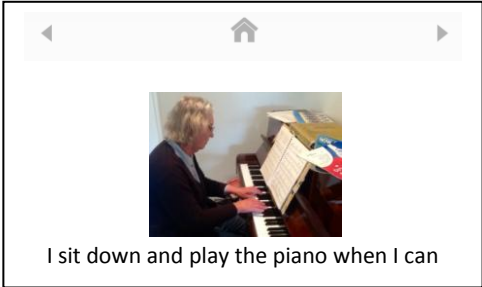
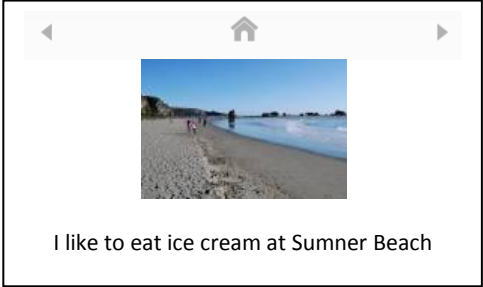
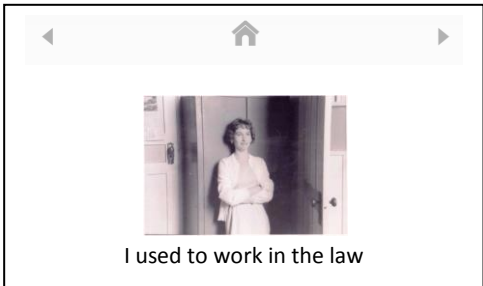
All phases of this study were conducted in the participants' homes, with the exception of two sessions involving Participant 2, which were conducted in a small private lounge area at a local day programme for people living with dementia. This change of venue for the participant was done at the request of the participant with dementia and his family member as the result of a conflict in their daily schedule. Sessions were conducted at a dining table with Participants 1 and 3 and in the lounge with Participants 2 and 4. During the sessions, the family members of Participants 1 and 3 sat in a nearby area during the sessions, while the family members of Participants 2 and 4 were often in an adjoining room, such as the kitchen opening out into the dining and/or lounge completing household tasks. The environment in all settings was modified to reduce distractions (e.g., television and radios turned off during the sessions). Each conversation was video recorded using a Panasonic PV-GS300 3.1 megapixel Multicam camcorder. The iPad was present during each conversation and placed into a "sleep" mode during baseline so that the memory aid was not accessed. Conversations were timed using a timer function on an iPhone.

2.5. *Stimuli*

The researcher worked in consultation with family members and the clients to develop a list of 10 facts related to each topic myself, family, and daily life, which were of personal relevance for each participant and which were used in the treatment and follow-up phases of the study. Corresponding photographs for the sentences were chosen by the family member from personal family albums. When photographs were unavailable, pictures related to the factual statements from Google Images were selected. An example of experimental stimuli and topic prompts are shown in Table 5.

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

Table 5. Sample Digital Memory Book Stimuli and Prompts

<u>Topic:</u>	Daily Life		
<u>Prompt:</u>	<i>"Tell me about what you enjoy in daily life"</i>		
<u>Example:</u>	<u>Photograph</u>	<u>Google Image</u>	
	 <p>I sit down and play the piano when I can</p>	 <p>I like to eat ice cream at Sumner Beach</p>	
<u>Topic:</u>	Family		
<u>Prompt:</u>	<i>"Tell me about your family"</i>		
<u>Example:</u>	<u>Photograph</u>	<u>Google Image</u>	
	 <p>[Name] and I have 2 children</p>	 <p>My mother and father both came from England</p>	
<u>Topic:</u>	Myself		
<u>Prompt:</u>	<i>"Tell me about yourself"</i>		
<u>Example:</u>	<u>Photograph</u>	<u>Google Image</u>	
	 <p>I used to work in the law</p>	 <p>I knit for Pregnant Pause</p>	

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

The digital memory books used in this study were constructed by the researcher using the *Pictello*™ application (version 1.6 developed by AssistiveWare, 2012) on an Apple iPad (iPad 2, model MC769X/A). The *Pictello* app was used to develop an individualised memory book for each participant. *Pictello*, is an application and available on iTunes™ for use with Apple iPad, iPhone, and iPod touch. The application requires iOS 5.1 or later and was last updated in November, 2012. The *Pictello*™ app does not require an active internet connection to use. It is available in English, Dutch, French, German, Spanish, and Turkish. For the purpose of this study, only the English language was used. Photos from family members were scanned using a colour scanner (Canon MP240) and uploaded to the researcher's iPad. The digital memory books consisted of a folder for each participant containing three separate folders for the topics myself, family, and daily life. Although *Pictello* has a voice output, this was not used within the study previous research has found that voice output may impede conversations for individuals with dementia (Fried-Oken et al., 2012). Each topic of conversation contained 10 pictures with a corresponding sentence. Each picture was displayed in the middle of the screen with the corresponding sentence written below in (font and font size). The participant could swipe or touch the side of the iPad to navigate between photos during the conversation. For the purpose of this study, each topic was created within a separate folder so that navigation between topics during baseline and treatment phases could be managed and accommodate for order effect. The researcher navigated between topics of conversation during the study.

2.6. Procedures

The study included administration of initial screening procedures followed by three phases: (a) baseline, (b) treatment, and (c) follow-up at two weeks post-treatment.

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

2.6.1. Initial Screening Procedures

The hearing and vision status of the participants was screened according to the *Memory Book Study Protocol* (Bourgeois, 1992). After obtaining consent from the participant (see appendix B) and family member participant (appendix C), vision and hearing were informally assessed by the researcher during conversation and participants were asked if they had glasses and/or hearing aids, and whether they regularly used these when conversing with others. The researcher then administered the following screening assessments (in order) to the participants with dementia during the initial session after consent had been obtained: (1) *Oral Reading Screen* (Bourgeois, 1992) adapted for iPad as a mock digital memory book using the *Pictello™* application to assess participants' oral reading ability, total words read accurately were summed (range 0-29); (2) *Spaced Retrieval Screen* (Brush & Camp, 1998) to examine participants' stimulability for learning how to turn the page on the digital memory book using spaced retrieval training; (3) *Addenbrooke's Cognitive Examination [revised] (ACE-R)* (Mioshi, et al., 2006) to screen participants' cognitive impairment; and (4) the *Functional Linguistic Communication Inventory (FLCI)* (Bayles & Tomoeda, 1995) to assess the communication profile for participants related to the Global Deterioration Scale (GDS) (Reisberg et al in 1982; as cited in Reisberg, 1990; SBU, 2008). The seven stages of the GDS describe expected functional ability from subjectively and objectively normal (GDS stages 1 and 2), mild cognitive impairment (GDS stage 3), early dementia (GDS stage 4), moderate dementia (GDS stage 5), moderately severe dementia (GDS stage 6), and severe dementia (GDS stage 7). Participant 1 and 4 scored within the mild-moderate range, and participants 2 and 3 scored within the moderate range. Screening sessions generally took 1 to 2 hours and were completed over one session.

2.6.2 Baseline, Treatment and Follow-up Phases

Baseline data were collected for three behaviours (i.e. novel on-topic statements during the three conversational topics of myself, family, and daily life). The intervention (i.e., digital memory

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

book) was introduced to one behaviour at a time (conversational topics) for a minimum of three sessions each. The three conversational topics were counterbalanced within each 5 minute session. Topics were chosen at random from the three established topics of conversation for each session using a die with each topic assigned two numbers between one and six (for example, the topic “My family” could be assigned a roll of number 1 or 4). The first topic for each baseline or treatment session was chosen randomly from the three topics of conversation using a die with each topic assigned two numbers between one and six.

The researcher began conversations in each of the baseline and treatment phases by stating, “This conversation will be videotaped for analysis. We’re going to have a 5 minute conversation about you, your family, and what you enjoy doing in daily life.” The iPad was present throughout all baseline sessions, facing the participant in sleep mode with a blank screen. At the beginning of the baseline phases, the researcher introduced the first topic by saying, “Please tell me about yourself (or family, or things you enjoy doing in daily life).” The count-down timer was started following the first prompt for each topic and made a sound to indicate topic change during the five minute conversation. When 90 seconds elapsed, the researcher then prompted the participant to talk about the second topic stating, “That was interesting. Now I’d like to know all about what you enjoy doing in daily life (or family)”. The researcher responded again with head nodding, smiles, and affirmations to express an interest in the content, show comprehension and/or confirmation, and as an encouragement for the participant to continue. When another 90 seconds had elapsed, the researcher thanked the participant and prompted him/her to talk about the final topic. The researcher did not interrupt when the participant produced ambiguous, unintelligible, or perseverative utterances. If 30 seconds of time elapsed with no response from the participant, the researcher repeated the prompt (e.g., “Would you tell me more about [the current specific topic]”, “What more can you tell me about [the current specific topic]”). The first treatment topic was

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

introduced after a minimum of three baseline sessions. Treatment of Topic 1 began with the experimenter introducing the digital memory book containing ten pictures and sentences related to the first topic:

Your family and I have made this memory book for you to use during our conversation [researcher presents memory book on the Apple iPad]. I will turn it on and open it for you. There are pictures and sentences in it so you can look at them to help you remember what you want to say. [Researcher will open to the specific treatment topic]. Let's talk about [specific treatment topic]. What can you tell me about [specific treatment topic]?

The count-down timer was started after the instructions provided to the participant to use the digital memory book. If no response was made by the participant after 30 seconds during the treatment phase, the researcher prompted the participant by asking "Would you tell me more about [the current specific topic]?" If no further response was made by the participant after another 30 seconds, the researcher prompted the participant to turn to a new page by saying "You can swipe your finger across the screen if you would like to see a new picture" or "You can change the picture by pressing the button on the top right". The prompt provided depended on participants' natural gesture for turning to a new picture on the iPad application. During treatment phases, topics of conversation were counterbalanced to eliminate order effect. The iPad's *guided access* was turned on during all sessions so that the application could not accidentally be turned off during treatment sessions. Between baseline and treatment topics, the iPad was switched into sleep mode with a blank screen and remained untouched in front of the participant. Digital memory book treatment sessions for the first topic were continued for a minimum of three sessions. The second treatment topic was then introduced and the researcher navigated between the two topic folders on the iPad application during conversations. These treatment sessions then continued for a minimum of three sessions. The final topic of conversation was then introduced and the treatment sessions continued

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

for a minimum of three sessions.. Each baseline and treatment session occurred on a separate day with a minimum of three sessions conducted within each week that the participant was in the baseline or treatment phase of the research. Maintenance of the digital memory book was assessed two-weeks after the last treatment session by conducting a conversation following the same procedure as in the final treatment session using the digital memory book for all topics of conversation (30 pictures and sentences in total). During all baseline, treatment, and follow-up conversation sessions conversation, the researcher sat quietly and responded with head nodding, smiles, and affirmations to express an interest in the content, to show comprehension and/or confirmation, and a to encourage the participant to continue. The researcher also responded to questions and would at times repeat a phrase said by the participant to acknowledge understanding and demonstrate active participation within the conversation. Short statements representing understanding (e.g., "Oh really?") were spoken in response to participants' appropriate elaborations on the current topic and served as an indirect encouragement for the participant to provide further information.

Each family member participant also participated in two five minute conversations with the participant with dementia. One session occurred prior to the introduction of the digital memory book and one time within 1-3 days after the follow-up session with the researcher. A second 5-minute conversational session in the maintenance phase was repeated on an alternate day by the family member participant from the researcher to examine generalisation. The family member participant used the same script as the researcher, and navigated between topics of conversation on the iPad application for the participant with dementia. The family member participant was trained how to turn pages and navigate between the three topics of the digital memory book on the *Pictello* application on the iPad. The iPad™ was not be left with the participants between sessions during the

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

course of the study. At the completion of the study, the family member participant also completed a questionnaire reflecting on their perceptions of the digital memory book.

2.7 Data Analysis

All sessions were video-recorded using a Panasonic (PV-GS300) Multicam Camcorder fixed to a tripod and positioned to view the participants during conversation. The video recordings were transcribed verbatim by the researcher.

Twenty percent of the total video files (20% from baseline and 20% from treatment sessions for each client) were independently transcribed by a research assistant. Overall reliability of the transcription was calculated by dividing the number of words in agreement by the total number of words in agreement plus in disagreement per transcript and multiplying by 100. This procedure produced an overall agreement score of 89.6% (range 87.3% to 92.4%).

The researcher coded each of the transcriptions for dependent variables and independent variables. The dependent variable was of Total On-Topic Statements (T), (a combination of the Memory Book statements (M) and Novel Statements (N)). The Total on-topic statements were graphed for analysis. Visual analysis of graphs allowed the researcher to identify trends in the dependent measures within and between phases for each participant (Kratchowill et al., 2010; McReynolds & Kearns, 1983). In addition, as described in previous research in the area by Bourgeois, the following non-targeted communication variables were also measured: Ambiguous Utterances (A), Unintelligible Utterances (U), Perseverative Utterances (P), Error Statements (E), and Other Utterances (O).. Similar to Bourgeois (1990), eight additional independent variables were measured to monitor treatment reliability: Partner Prompts (PP), Partner Statements (PS), Partner Questions

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

(PQ), Partner Others (PO). These conversation codes were defined by Bourgeois (1990) to analyse all conversational utterances between the researcher and the participants. Another independent variable was included to measure Non-partner Utterances (NP). This included prompts, statements, and questions. In the current study, it was observed that family members would at times add content to the conversation when the researcher was acting as the “conversational partner” and impacted on participant utterances. Definitions of these codes are included in Table 6.

Table 6. Definitions of Conversational Codes

Code	Definition
Participant	
Memory Book statement (M)	Memory book statement: one of the 30 sentences produced unambiguously and intelligibly.
Novel on-topic statement (N)	Intelligible, unambiguous statements contributing additional correct information related to the topic (e.g., comment related to the stimuli, elaboration of a prior statement).
Total on-topic statements (T)	Total of the novel on-topic statements in addition to any Memory Book statements.
Ambiguous (A)	Intelligible utterance but ambiguous in content due to one or more of the following: <ul style="list-style-type: none"> a) Empty phrase: a phrase or idiom contributing no content to the conversation b) Indefinite term: utterances containing highly non-specific nouns (e.g., stuff, thing, something). c) Deictic term: terms with no referents to the precise meaning (e.g., this, that, here, there). d) Pronouns without antecedents: pronouns used without specific referents.
Unintelligible (U)	Sentence fragments, grammatically incomplete phrases, non-English phrases, multiple joined sentence fragments, and any utterances containing neologisms, literal, verbal, semantic, or phonological paraphasias.
Perseverative (P)	Repetitions of previously stated information (single words, phrases, or complete sentences)

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

Error (E)	Intelligible and unambiguous statements related to the topics of conversation and expressing a fact that is false, as determined by the family member participant.
Other (O)	<ul style="list-style-type: none"> a) Any intelligible and unambiguous speech, such as requests, questions, responses to questions, commands, or acknowledgements (including repetition of a statement for acknowledgement purposes). b) Any intelligible and unambiguous utterances that expresses a fact unrelated to the topic of conversation (e.g., an unrelated topic, a statement of fact related to previous topic of conversation) c) Any intelligible and unambiguous utterance that answers a direct question asked by the Partner or Non-partner (e.g., “who is this?” “what is your son’s name?”)

Researcher

Prompt (PP)	Any of the three prompts (tell me about yourself/your family/your daily life) .
Statement (PS)	Statements adding content to the conversation and not one of the specific partner prompts or a direct question.
Question (PQ)	Question requesting direct information from the participant.
Other (PO)	Any other speech act that serves to regulate conversation without providing content (e.g., acknowledgements such as “I see”, “oh wow”. “alright”), or organisational devices that serve to regulate the conversation and social conventions (e.g., timer going off to signify change of topic or end of conversation).

Non-Partner

Utterances (NP)	Any of the three prompts (tell me/us/researcher about yourself/your family/your daily life), statements which added content to the conversation, questions requesting direct information from the participant when not an active conversational partner during baseline and treatment phases.
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A research assistant participated in training on coding with the researcher. This training involved discussing the dependent and independent variable definitions and practicing coding one conversation from each participant which was not used for reliability. The calculation of point-by-point inter-observer agreement was then completed by having the research assistant code and score 20% of the transcripts from each baseline and treatment phase for each client and these were compared to those of the researcher. The mean inter-observer agreement for the dependent and

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

independent participant variables coded per session for each client was Participant 1: 88.5% (range: 83.7% to 93.2%); Participant 2: 93% (range: 89.8% to 95.8%); Participant 3: 89.8% (range: 87.3% to 94%); and Participant 4: 93% (range: 89.8% to 95.9%). The average inter-observer agreement for the coded researcher and non-partner independent variables for each client was 97.3% (range: 96.2% to 99%).

3. Results

3.1. *Effects of a digital memory book on the quantity and quality of conversations of adults with a mild to moderate dementia*

3.1.1 *Participant 1*

The baseline, treatment, and follow-up results for Participant 1 are presented in Figure 1. Visual analysis of the total-on-topic statements revealed a lack of evidence of a clear difference between baseline and treatment phases for features such as level, trend, and overlap of data points (Kratochwill, Hitchcock, Horner, Levin, Odom, Rindskopf, & Shadish, 2010; McReynolds & Kearns, 1983). During the baseline phase, Participant 1's total-on-topic statements ranged from 3 to 4 statements for the topic of family, 4 to 8 for the daily life topic, and 2 to 6 for the topic of myself. In the treatment phase, his total-on-topic statements ranged from 1 to 11 for the family topic, 3 to 11 for the daily life topic, and 3 to 14 for the topic of myself. During the follow-up session, two weeks after the last treatment session, Participant 1's total-on-topic statements with the digital memory book decreased from 7 in the last treatment session to 5 for the both the family topic and daily life topic, while the number of total-on-topic statements remained unchanged for the topic of myself. The follow-up data points for all three topics overlapped with the baseline ranges for both the second and third treatment topics, and remained above the baseline range for the first treatment topic of family.

During the baseline and treatment phase Participant 1 tended to comment on recent relationships for the family topic, such as talking about his wife and children, or a good friend who visited him at home. In the baseline phase, he would often repeat statements such as, "I don't know", or "nothing, just nothing" when discussing the topics of daily life and myself. In treatment

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

sessions, Participant 1 only read the memory book statements three times for the first topic during the very first treatment session. Participant 1 made general comments on the pictures when they were presented in the treatment phase (e.g. [Pointing to and looking at a photo of himself in his chair in front of the television] “That’s my favourite position”).

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

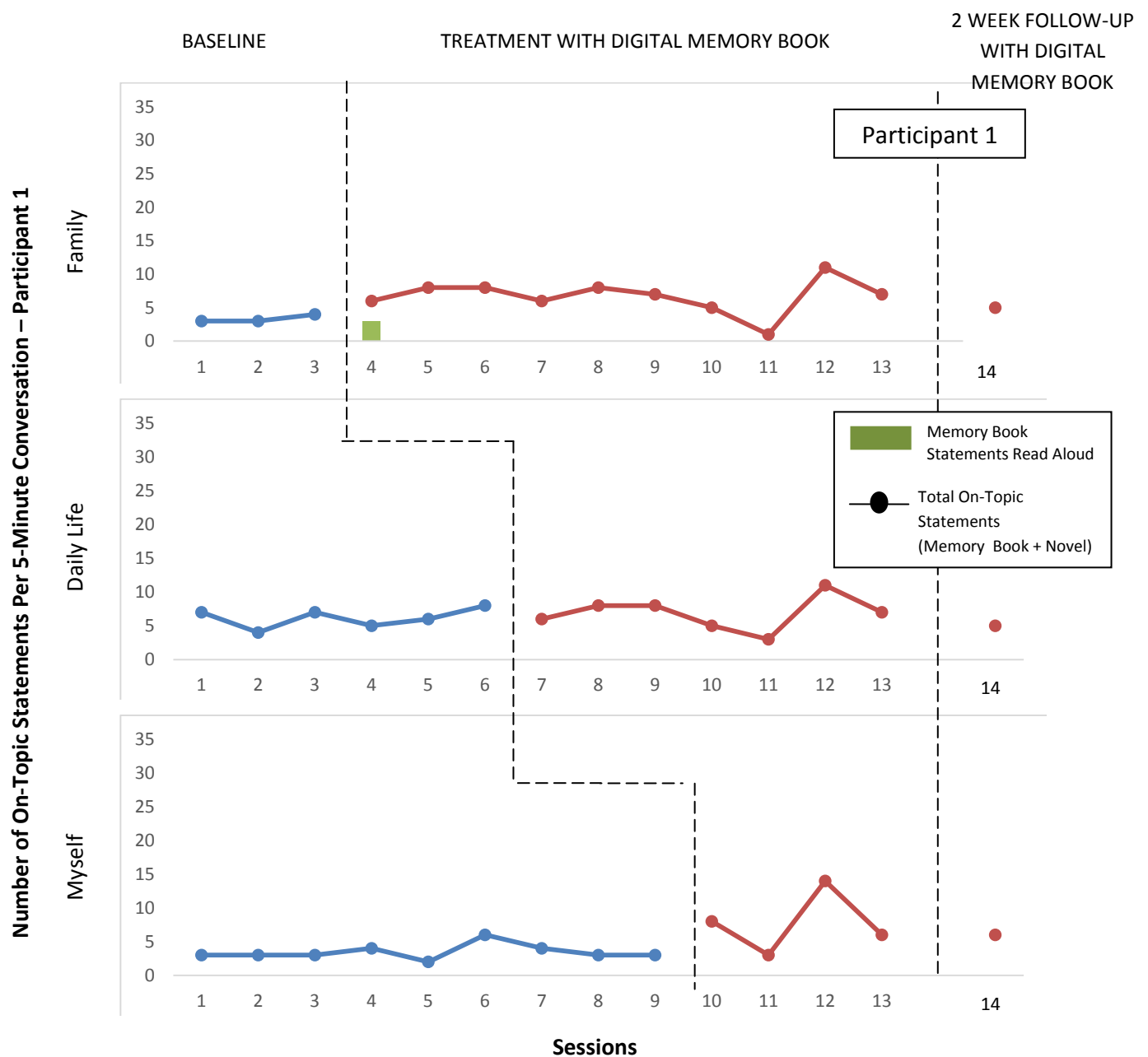


Figure 1. Participant 1's number of on-topic statements. Number of total on-topic, including memory book statements Participant 1 made during 5-minute conversations across all topics during baseline and treatment phases in each session. Line graphs represent the number of total on-topic statements (Memory Book statement (M) and Novel (N) Statements). Bar graph represents the number of Memory Book statements (M) read aloud.

3.1.2 *Participant 2*

Figure 2 shows the baseline, treatment, and follow-up results for Participant 2. Visual analysis of the total-on-topic statements revealed a lack of evidence of a clear difference between baseline and treatment phases for features such as level, trend, and overlap of data points for the topics of daily life and my family. (Kratochwill, et al., 2010; McReynolds & Kearns, 1983); however, there was an overlap of data points between the baseline and treatment phases for the topic of myself. Participant 2's total-on-topic statements ranged from 0 to 1 for the daily life topic, 0 to 7 for the topic of my family, and 0 to 3 for the topic of myself during the baseline phase. In the treatment phase, Participant 2's total-on-topic statements ranged from 0 to 11 for the daily life topic, 4 to 9 for the topic of my family, and 4 to 9 for the topic of myself. During the follow-up session, two weeks after the last treatment session, Participant 2's total-on-topic statements increased from 11 in the last treatment session to 14 for the daily life topic, from 7 to 11 for the topic of my family, and from 9 to 16 for the topic of myself.

Participant 2 provided varied statements during the baseline sessions, although, he frequently talked about how his family like to help people for both the topic of family and myself. During the treatment phase, Participant 2 required prompts from the researcher to turn to the next picture on the iPad when he had no more to say about a picture (i.e., "You can change the picture by pressing the button on the top corner"). It was also observe that Participant 2 would periodically produce unintelligible words within an utterance which resulted in coding the utterance unintelligible when it was otherwise a novel on-topic statement (e.g., "This is my father here, he was a very XXX wonderful uh, father" [when talking about a picture of his parents]). During the treatment sessions, the participant rarely read the memory book statements out loud.

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

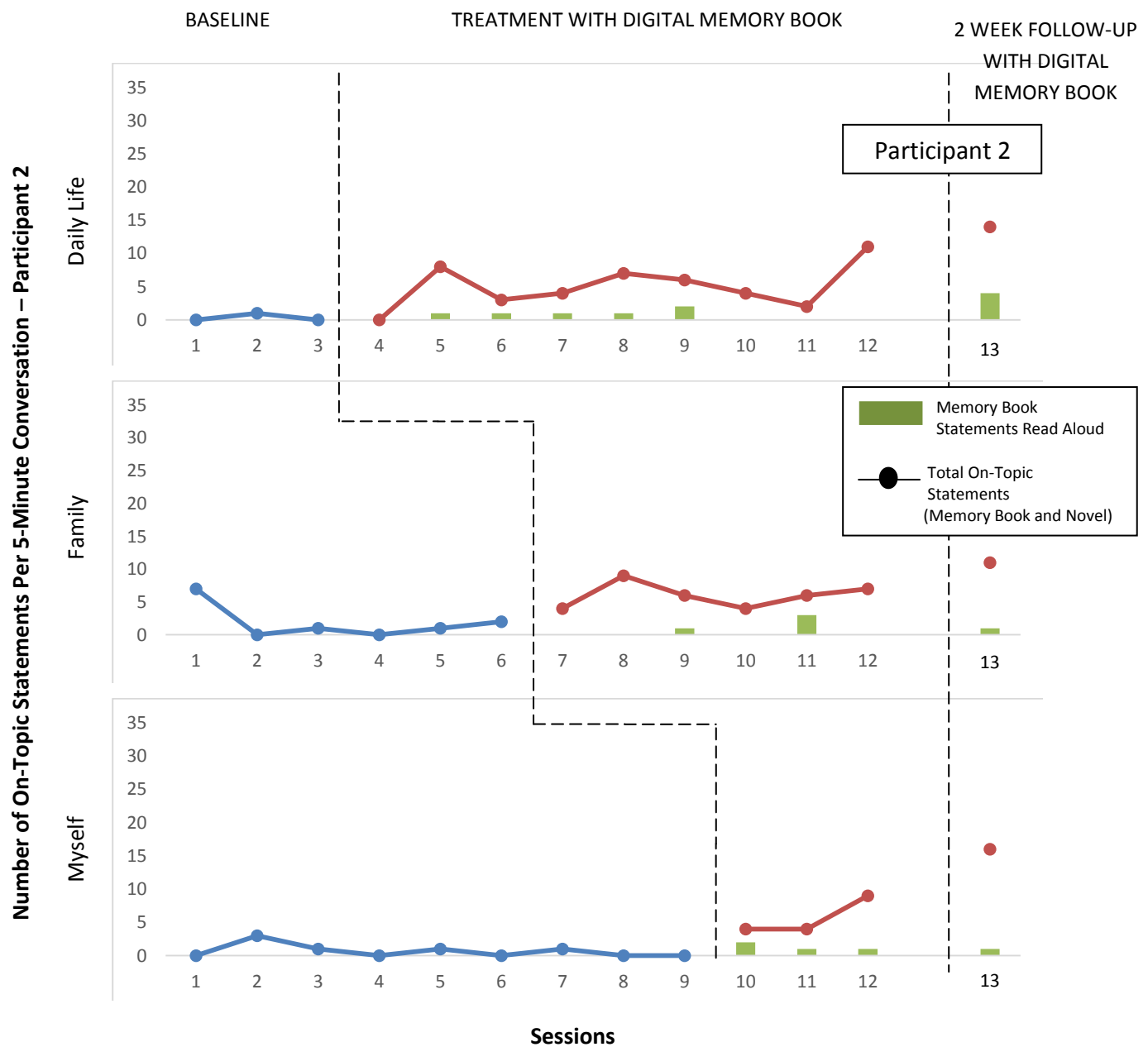


Figure 2. Participant 2's number of on-topic statements. Number of total on-topic, including memory book statements Participant 2 made during 5-minute conversations across all topics during baseline and treatment phases in each session. Line graphs represent the number of total on-topic statements (Memory Book statement (M) and Novel (N) Statements). Bar graph represents the number of Memory Book statements (M) read aloud.

3.1.3 Participant 3

The baseline, treatment, and follow-up results for Participant 3 are displayed in Figure 3. Visual analysis of the total-on-topic statements revealed a lack of evidence of a clear difference between baseline and treatment phases for two of the three topics for features such as level, trend, and overlap of data points (Kratochwill, et al., 2010; McReynolds & Kearns, 1983). There was no overlap of data points between the baseline and treatment phases for the topics of my family and myself. There was no overlap of data points between the baseline and treatment phases for the daily life topic, however, there was a downward trend for the last two treatment phase sessions for this topic. During the baseline phase, Participant 3's total-on-topic statements ranged from 6 to 7 for the topic of my family, 0 to 6 for the topic of myself, and 0 to 3 for the daily life topic. During the treatment phase, Participant 3's total-on-topic statements ranged from 4 to 15 for the topic of my family, 3 to 17 for the topic of myself, and from 5 to 10 for the daily life topic. The baseline sessions for the topic of myself were variable. Participant 3's total-on-topic statements increased from 13 in the last treatment session to 18 in the follow-up session for the topic of my family. The statements decreased to 5 from 17 in the last treatment session for the topic of myself, and remained unchanged for the daily life topic. The follow-up data points for the second treatment topic, myself, overlapped with the baseline ranges and did not overlap for the topics of my family and daily life.

During baseline sessions, Participant 3 tended to perseverate on the first topic introduced in the session. Participant 3 tended to limit statements to a particular period of time in her life when she was in her twenties when talking about the topics of myself and my family. It was informally noted that when this occurred during treatment phases, the picture stimulus would prompt conversation about this period of time, and the presence of a sentence prompt was not helpful in maintaining topic of conversation. An example of this is when Participant 3 was looking at a photo of

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

Britain with the Memory Book statement “my mother and father both came from England”, would indicate where her parents came from, pointing to the map, then continue to talk about when she worked in England in her twenties. During the treatment phase, Participant 3 would frequently only talk about one or two pictures per treatment topic. She would often repeat the same novel utterance when certain pictures were presented on the digital memory book. For example, when presented with a picture of Army servicemen gathered in the streets of Christchurch, New Zealand, and the sentence “My father went to war after I was born”; she would consistently respond, “Yes, and when he came back I didn’t know who this man was!”. For all three treatment topics, although initial statements would be related to the picture and sentence, she would then discuss a topic unrelated to the treatment topics. Participant 3 would sometimes produce an unintelligible word within a statement which resulted in the coding for the whole utterance to be unintelligible when it was an otherwise novel on-topic statement (e.g., “No, I.. we, we didn’t go to the XXX [pool]” [when Participant 3 was talking about going swimming]). Participant 3 rarely read the memory book statements aloud.

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

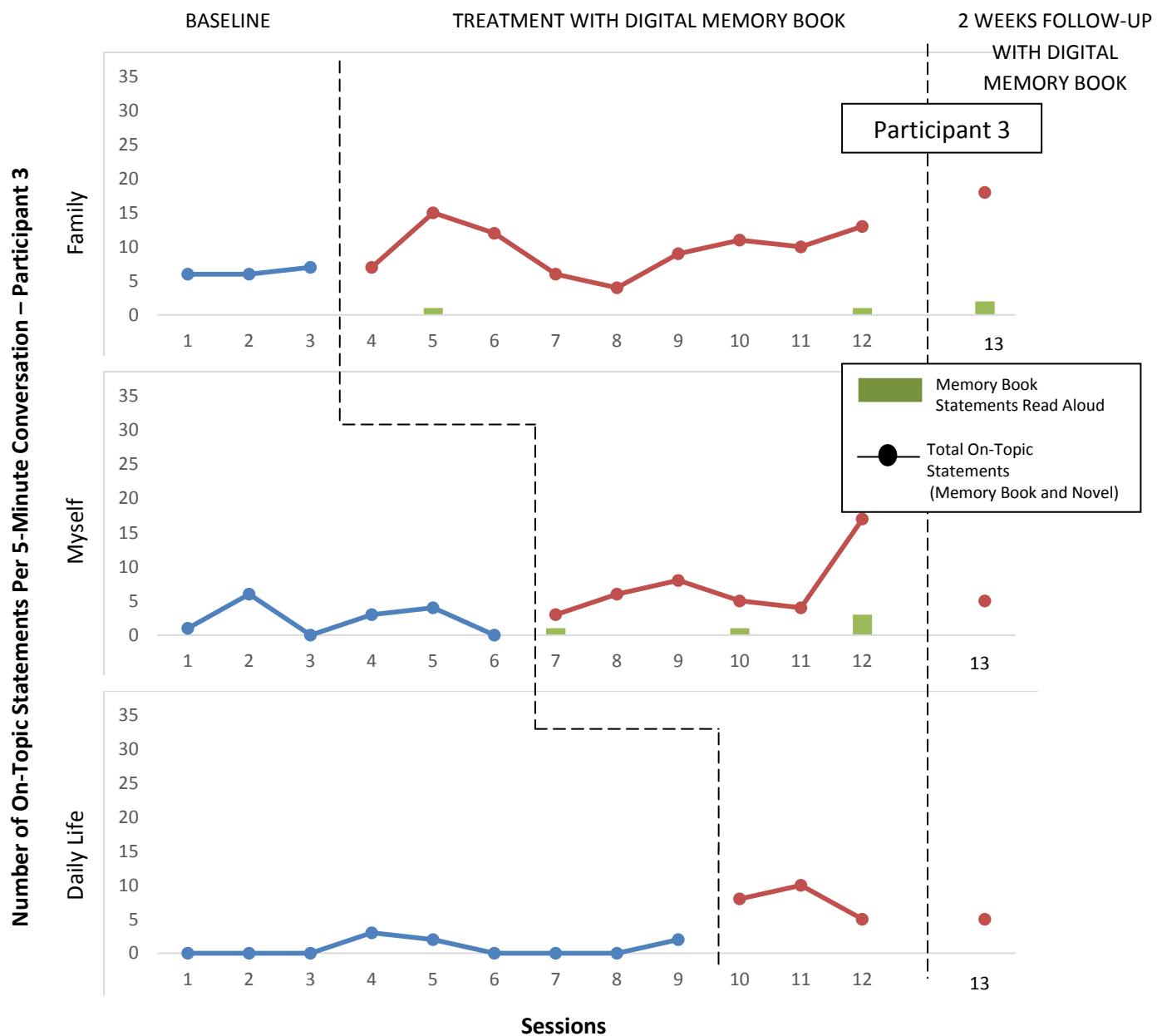


Figure 3. Participant 3's number of on-topic statements. Number of total on-topic, including memory book statements Participant 3 made during 5-minute conversations across all topics during baseline and treatment phases in each session. Line graphs represent the number of total on-topic statements (Memory Book statement (M) and Novel (N) Statements). Bar graph represents the number of Memory Book statements (M) read aloud.

3.1.4 Participant 4

The baseline, treatment, and follow-up results for Participant 4 are presented in Figure 4. Visual analysis of the total-on-topic statements revealed a lack of evidence of a clear difference between baseline and treatment phases for features such as level, trend, and overlap of data points (Kratochwill, et al., 2010; McReynolds & Kearns, 1983). During the baseline phase, Participant 4's total-on-topic statements ranged from 4 to 9 for the topic of myself, 2 to 12 for the daily life topic, and 0 to 30 for the topic of my family. Participant 4's total-on-topic statements during the treatment phase ranged from 5 to 28 for the topic of myself, 6 to 16 for the daily life topic, and 13 to 18 for the topic of my family. The baseline phases for two of the topics (daily life and family) for this participant were quite variable.

Two weeks after the last treatment session, during the follow-up session with the digital memory book, Participant 4's total-on-topic statements decreased from 12 in the last treatment session to 9 for the myself topic, decreased from 8 in the last treatment session to 3 for the daily life topic, and increased from 14 in the last treatment session to 22 for the family topic. The follow-up data points for all three topics overlapped with the baseline ranges for all three topics.

During baseline and also treatment sessions, Participant 4 would often talk about living with dementia as a "young person" (under 65) and the impact this has had on his family and on his loss of independence for the topics of *daily life* and *myself*. During the treatment phase, Participant 4 required prompts from the researcher to turn to the next picture on the iPad when he had no more to say about a picture (i.e., "You can change the picture by pressing the button on the top corner"). After the third baseline session, Participant 4 would often comment, "You know all this" or "We've

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN
ADULTS WITH MILD TO MODERATE DEMENTIA

done this” following prompts to talk about each topic. Participant 4 rarely read the memory book
statements aloud.

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

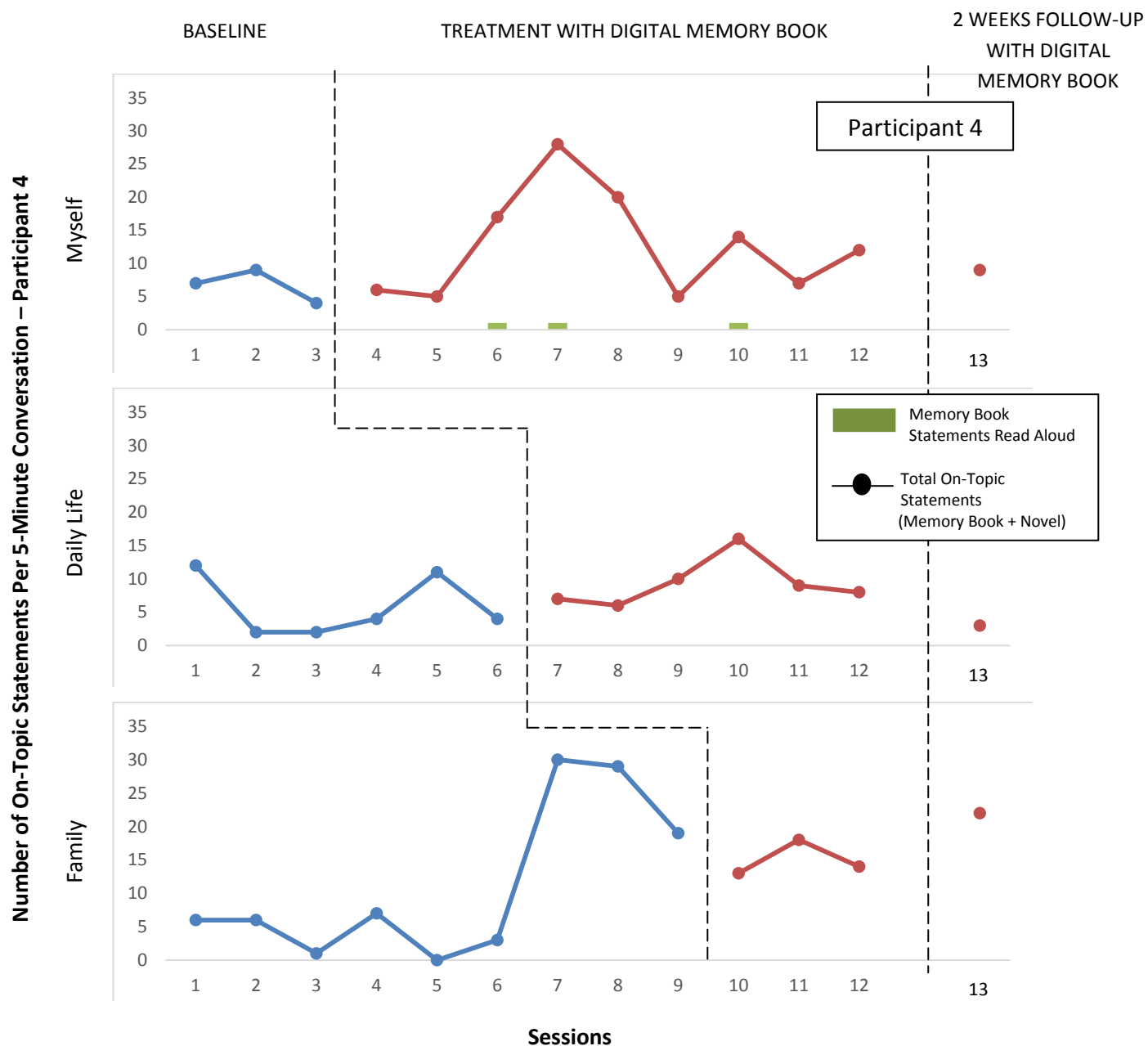


Figure 4. Participant 4's number of on-topic statements. Number of total on-topic, including memory book statements Participant 4 made during 5-minute conversations across all topics during baseline and treatment phases in each session. Line graphs represent the number of total on-topic statements (Memory Book statement (M) and Novel (N) Statements). Bar graph represents the number of Memory Book statements (M) read aloud.

3.2. Effects of the digital memory book on total-on-topic statements during conversations with the family member participant

Additional measures were also obtained to investigate whether there was a generalisation of total on-topic statements to conversations between the participants with dementia and their family members. Total on-topic utterances for the baseline and follow-up sessions involving family members as the conversation partner are presented in Figure 5. Visual analysis of these sessions revealed that Participant 1's total-on-topic statements increased from 3 statements in baseline to 8 statements in follow-up with the digital memory book for the topic of my family, from 3 to 6 statements for the daily life topic, and from 2 to 8 statements for the myself topic. Participant 2's on-topic statements increased from 2 statements in baseline to 5 statements in follow-up with the digital memory book for the daily life topic, from 4 statements to 5 statements for the topic of my family, and from 4 statements to 7 statements for the topic of myself. Participant 3's on-topic statements increased from 3 statements in baseline to 22 statements in follow-up with the digital memory book for the topic of my family, 1 statement to 12 statements for the topic of myself, and 0 statements to 9 statements for the daily life topic. Participant 4's on-topic statements increased from 0 statements in baseline to 12 statements in follow-up with the digital memory book for the topic of myself, 0 statements to 9 statements for the daily life topic, and from 2 statements to 19 statements for the topic of my family.

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

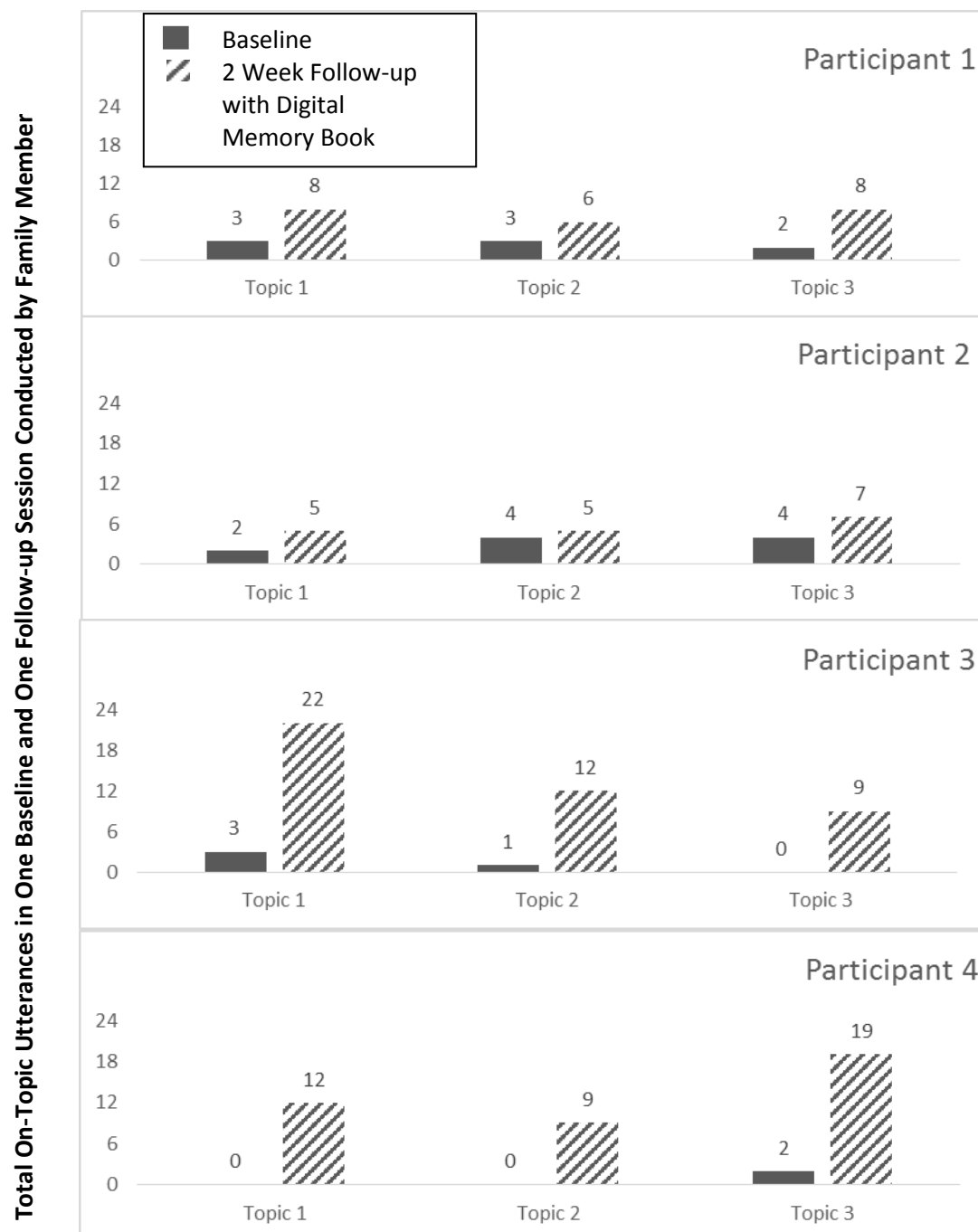


Figure 5. Total on-topic utterances in one baseline and one maintenance session in which the family member participant acted as the conversation partner.

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

Following the final session, the family member participants were asked to fill in a questionnaire regarding their thoughts on using a digital memory book to facilitate conversation. All family member participants agreed or strongly agreed that the digital memory book was easy to use and made having a conversation with the person with dementia easier. They neither agreed nor disagreed with the statement that their family member with dementia made positive statements following conversations using the digital memory book with the researcher. All family member participants agreed or strongly agreed that the digital memory book was relevant and that they would choose to continue to use a digital memory book during conversations with their family member with dementia outside the study, if they had access to one.

3.3. Participants' non-targeted communicative behaviours

The mean frequencies of all other non-targeted communicative behaviours were also analysed and are presented in Figure 6. All participants reduced their ambiguous utterances (Participant 1: 0.5 to 0.4; Participant 2: 5.3 to 3.2; Participant 3: 8.2 to 6; Participant 4: 3.4 to 3.2) between baseline and treatment phases. Participant 2 reduced his unintelligible utterances, whilst Participant 1 remained stable, and an increase in unintelligible utterances was observed for Participants 3 and 4 (Participant 1: 0 to 0; Participant 2: 3.7 to 3.1; Participant 3: 2.2 to 5; Participant 4: 1.8 to 2.2). Participants 1 and 4 reduced their perseverative utterances, whereas Participant 2 showed an increase and Participant 3 remained stable between baseline and treatment phases (Participant 1: 1.8 to 0.5; Participant 2: 0.5 to 0.7; Participant 3: 0.7; Participant 4: 0.9 to 0.6). Error utterances were low for all participants, with Participants 1 and 3 making no error statements, Participant 2 showing an increase, and Participant 4 showing a decrease in error statements between baseline and treatment phases (Participant 1: 0 to 0; Participant 2: 0 to 0.1; Participant 3: 0 to 0; Participant 4: 0.6 to 0). Participants 1 and 4 demonstrated a reduction in other utterances,

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN
ADULTS WITH MILD TO MODERATE DEMENTIA

while Participants 2 and 3 demonstrated an increase (Participant 1: 4.3 to 1.2; Participant 2: 6.2 to 8;
Participant 3: 6 to 8.6; Participant 4: 16.5 to 12.3).

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

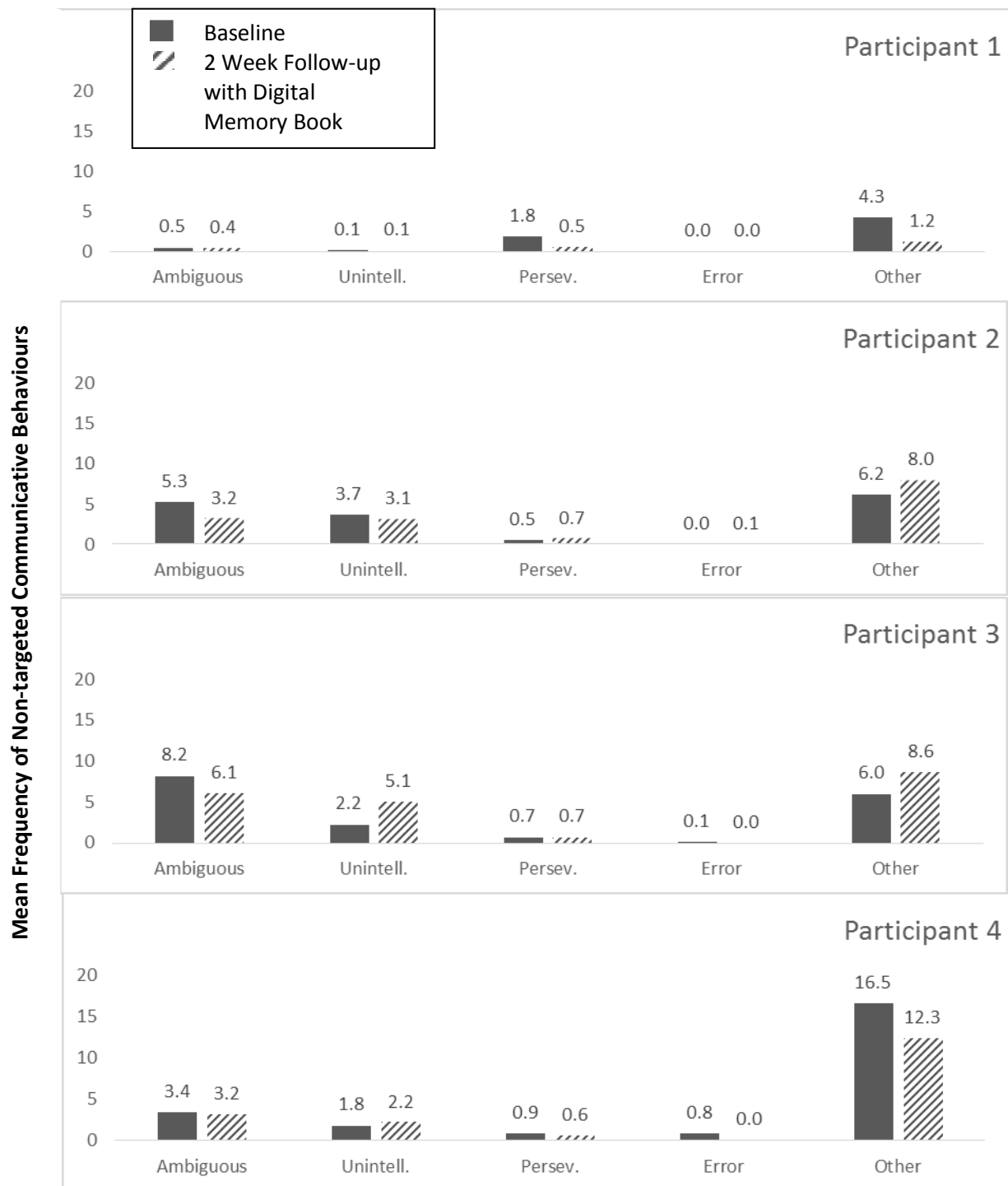


Figure 6. Mean frequency of non-targeted communicative behaviours (ambiguous, unintelligible, error, perseverative, and other utterances) of Participant 1, 2, 3, and 4's during 5-minute conversations in baseline and treatment sessions. The solid bars represent the mean of particular non-targeted communicative behaviours across all three topics during baseline sessions. The hatched bars represent the mean of particular non-targeted communicative behaviours across all three topics during treatment sessions.

3.4. *Communication Partner Utterances*

The three independent variables of Partner Prompts, Partner Statements, and Partner Other Statements were measured to monitor the fidelity of the treatment (Bourgeois, 1990). Although the family members did not sit with the researcher and the participant with dementia during the baseline and treatment sessions, the family members of Participant 2 and 4 spoke on a few occasions during the initial baseline sessions (e.g. Participant 1 had responded “No” to the Partner Prompt “Is there anything more you can tell me about you” and his wife then asked him “What about your likes and dislikes?”; and when Participant 4 had responded negatively to the Partner Prompt “...I’d like to know all about yourself” stating that he was boring and frustrated, his wife responded “good things love”). An additional category (Non-Partner utterances) not identified in the Bourgeois (1990) study was used to code any of these utterances made by family members. The mean frequencies of each of the Partner Utterances and all Non-Partner Utterances are displayed in Figure 6. The data show that the researcher was relatively consistent in the mean number of topic prompts given and questions asked across phases of the study for all the participants. Partner Other utterances (such as “mmhmm” and “yeah”) were at a higher frequency in treatment phases than in baseline for Participants 1, 2, and 3; with a decrease in Partner Other utterances recorded for Participant 4 (Participant 1: from 2.94 to 5.83; Participant 2: from 5.87 to 8.35; Participant 3: from 4.29 to 11.07; Participant 4: from 10.15 to 8.35).

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

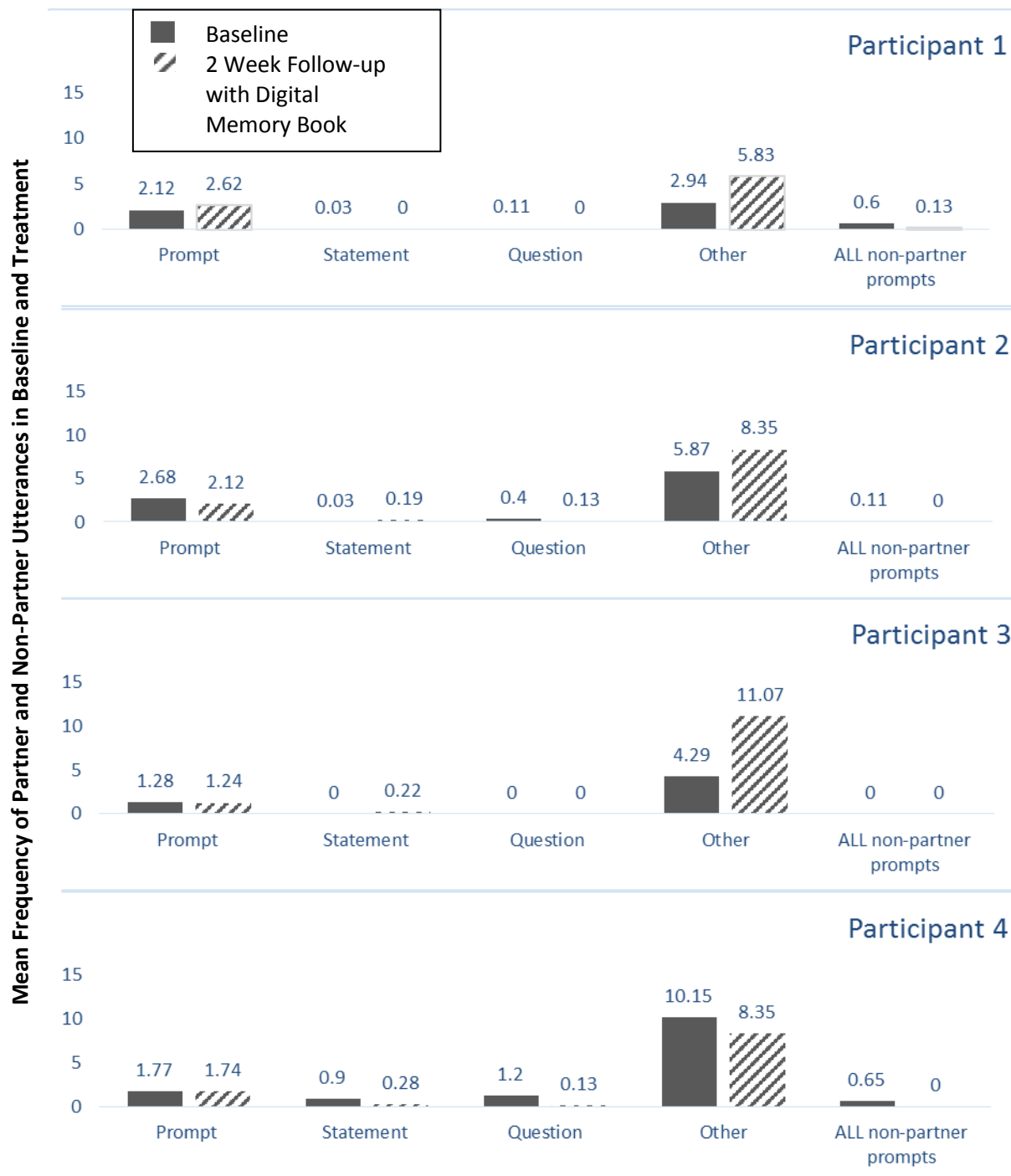


Figure 7. Mean frequency of Partner and Non-Partner Utterances (Partner Prompts, Partner Statements, Partner Questions, Partner Others, and total All Non-Partner Prompts) with participants 1, 2, 3 and 4 during 5-minute conversations in baseline and treatment sessions. The solid bars represent the mean of partner utterances across all three topics during baseline sessions. The hatched bars represent the mean of partner utterances across all three topics during treatment session

3.5 *Summary of results*

The findings revealed that there were no clear differences between the baseline and treatment phases for all three topics for Participants 1 and 4 and for two of the three topics for Participants 2 and 3. The baseline phases for one of three topics for Participant 3 and two of three topics for Participant 4 were quite variable. During the follow-up sessions with the digital memory book, two weeks after the last treatment sessions, the total-on-topic statements for two topics for Participant 1 (daily life and myself), one topic (myself) for Participant 3, and for all three topics for Participant 4 overlapped with the baseline data points. The participants with dementia rarely read the memory book statements aloud during the treatment phases of the study. All participants reduced the mean frequency of their ambiguous utterances between the baseline and treatment phases, while Participants 3 and 4 increased the mean frequency of unintelligible utterances between these two phases. All participants increased their total-on-topic statements during conversations with their family members for all three topics from an initial baseline session to a follow-up session involving the digital memory book at the end of the study.

4. Discussion

4.1. *Effects of the digital memory book on the quality and quantity of conversations*

The purpose of this study was to evaluate the effects of a digital memory book on the quality and quantity of conversations of adults with mild to moderate dementia. The results of this investigation indicated that a digital memory book did not improve the quality and quantity of conversations that the participants had with the researcher. These findings differ from the results of previous research involving low technology memory books. In the following section, the current study is discussed in relation to these earlier investigations.

First, unlike some of the previous studies in the area (Bourgeois, 1990; 1992), this investigation included participants with mild to moderate dementia. As the study progressed, three participants in the current investigation reported that they remembered going over the topics in previous research sessions, making comments to the researcher such as “You know all this” and “Haven’t we done this?” The inclusion of participants with a milder dementia in the study may have negatively affected the outcome of the study. It is possible that memory books may be more effective in improving the conversations of individuals who have more significant memory impairments as the result of a moderate or more severe dementia. Future studies in this area may focus more on including individuals with a moderate or more severe dementia.

Second, unlike most of the participants in previous studies in the area (Bourgeois, 1990; Bourgeois, 1992; Chang & Bourgeois, 2012), participants in the current investigation rarely read the memory book statements aloud during the treatment sessions. As a result, almost all of the participants’ total-on-topic statements during the treatment phase sessions were novel utterances. Rather than reading the statements aloud, at times, it appeared to the researcher that the

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

participants were silently reading the statements about the pictures. For example, after apparently silently reading the digital memory book statements they made comments about the written sentences (e.g., saying, “Oh yes! Yes, that’s right. Mm-hmmm” when the following statement was on the iPad screen: “I like spending time with Hattie, the dog!” and saying, “Yes, I do that” when this statement was on the iPad screen: “I go to the [name of club] Club three days a week”). At other times, it appeared to the researcher that the participants were focusing on the pictures on the iPad screen, rather than silently reading the statements (e.g., saying, “I’m not sure where this is?” when the following photo and statement were on the iPad screen: “I worked as a plumber in my own business [name of business]”). This difference from previous studies may relate to the inclusion of individuals with mild to moderate dementia in the current study who chose not to read most of the memory book statements aloud, recognising that the researcher could also see the sentences. Another reason for this difference could be that the bright digital screen photos on the iPad drew the participants’ attention away from the written sentences.

The use of high-tech digital technology rather than a low-tech paper-based memory book may have also affected the outcomes obtained in this study. Fried-Oken et al. (2012) reported that the novelty of an AAC device (i.e., presence of audio output) appeared to prevent some of the participants with dementia in their study from conversing. In the current investigation, the novelty of the iPad device itself may have negatively affected the conversational output of the participants during the treatment phase. For example, during a treatment session, one participant wondered how the researcher had obtained older photos of his family and put them on the iPad (e.g., Participant 2: “Look at these [older photos of his family]! How did you get these here [on the iPad screen]?”). Three of the four participants in the study reportedly had not used an iPad or other tablet prior to the investigation. Research in the future could focus on individuals who are more familiar with the use of iPads or tablets or could include a tablet training component as part of the

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

study.

Variable baseline performance of two of the participants in the investigation may have also negatively affected the study outcomes (McReynolds & Kearns, 1983). Performance during baseline phases for two of three topics for Participant 4 and for one of three topics for Participant 3 was quite variable. Similarly, the one participant in the study by Bourgeois (1992) who initially demonstrated relatively small effects in relation to the use of a low technology memory wallet also reportedly demonstrated more variable baseline performance than the other participants.

Specific characteristics of the participants may also have affected the outcomes of the study. For example, Participant 1's family member indicated that prior to the study that the participant had demonstrated reduced motivation and initiation, which had a major impact on his day-to-day conversation. Future studies may need to consider these factors within the inclusionary criteria for participants.

Another aspect of the study that may have negatively affected the performance of two of the participants with dementia involved the coding of unintelligible utterances. Participants 3 and 4 increased their mean frequency of unintelligible utterances between the baseline and treatment phases. The researcher noted that these participants sometimes appeared to speak more quickly during the treatment sessions, possibly attempting to express more information about a topic when using the digital memory books. However, utterances in which the participants had one or more unintelligible words were not coded as on-topic statements. Use of the percentage of total conversation time focusing on topic-related conversation as a measure may be useful in overcoming this issue in future studies (McPherson, Furniss, Sdogati, Cesaroni, Tartaglini, & Lindesay, 2001).

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN ADULTS WITH MILD TO MODERATE DEMENTIA

Although the study found that there was no evidence that the digital memory book had a positive effect on the quality and quantity of the conversations of the individuals with mild to moderate dementia with the researcher, there were some positive findings involving the conversations between the individuals with dementia and their family members. For example, the number of total-on-topic statements increased substantially between the baseline and the follow-up sessions involving the family members for all behaviours for Participants 1, 3, and 4 and for two of the three behaviours for Participant 2. Following the final session, family members were asked to fill in a questionnaire regarding their thoughts on using a digital memory book to facilitate conversation. All the family member participants agreed or strongly agreed that the digital memory book was easy to use and that it made having a conversation with the individual with dementia easier. Family member participants also agreed or strongly agreed that the digital memory book was relevant and that they would choose to continue to use a digital memory book during conversations with their family member with dementia outside the study if they had access to one. Participant 4's family member also reported that a positive outcome of the study was having the opportunity to go through old photos with the individual with dementia and to talk about the family and holidays they had enjoyed together. Future research could investigate the use of the digital memory book with family members in more depth.

4.2. Limitations

The study had some limitations that need to be considered. First, although the researcher was relatively consistent in the mean number of topic prompts given and questions asked across phases of the study for all the participants, variability was observed in relation to the number of Partner Other Utterances across the phases. This finding is consistent with the results of the study by Chang and Bourgeois (2012). The Partner Other Utterances consisted of speech acts that served to regulate conversation without providing content (e.g., acknowledgements such as "I see", "Oh wow"

and “Alright”), and organisational devices that served to regulate the conversation and social conventions. The increase number of these type of utterances may reflect the researcher responding to an increased number of on-topic utterances by the participants. Future studies may need to consider how to modify procedures to ensure more consistent use of these types of utterances across the phases.

Unlike previous studies in the area, the category of Non-Participant Utterances was included in this investigation to code any family member utterances during the baseline and treatment phases. As part of the ethics protocol for this study, family members were able to be present in the same room during the baseline and treatment phases of the study. The family members did not sit with the researcher and the participant with dementia during these sessions. Prior to the beginning of the initial baseline session, the family members were also advised by the researcher that it was important for them not to talk during the researcher’s research sessions with the participants with dementia. Despite these procedures, the family members of Participant 2 and 4 spoke on a few occasions during the initial baseline sessions (e.g. Participant 4 had responded negatively to the Partner Prompt “...I’d like to know all about yourself” stating that he was boring and frustrated, to which his wife responded “good things love”) and the family member of Participant 1 spoke on a few occasions during the initial baseline and treatment sessions (e.g., “It’s really hard for me to listen to him like this). Future investigations in the area may need to consider how to address this issue.

5. Conclusion

Although the study found that the use of a digital memory book did not improve the quality and quantity of conversations in adults with mild to moderate dementia, further research in the area is warranted. Future investigations could involve individuals with moderate or more severe dementia and individuals who are familiar with using digital media in their daily lives. Research could also focus more on the use of digital memory books during conversations with family members.

THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN
ADULTS WITH MILD TO MODERATE DEMENTIA

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THE EFFECTS OF A DIGITAL MEMORY BOOK ON THE QUALITY AND QUANTITY OF CONVERSATIONS IN
ADULTS WITH MILD TO MODERATE DEMENTIA

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Study Title What are the effects of a digital memory book on the quality and quantity of conversations in adults with mild-moderate dementia?

Researcher Katrina A. Aitken

- You (the participant) are being asked to be in a research study. Studies are done to find better ways to treat people or to understand things better.
- This form will tell you about the study to help you decide whether or not you want to participate.
- You should ask any questions you have before making up your mind. You can think about it and discuss it with your whānau/family or friends before you decide.
- It is okay to say “No” if you do not want to be in the study. If you say “Yes” you can change your mind and quit being in the study at any time without any penalties.

1. What is this study about?

This study is trying to find out if it is easier to talk about your life and your whānau /family when you look at pictures or read sentences about them using an *Apple iPad™* (small computer).

2. What will I need to do if I am in this study?

You will be shown memory aids with pictures and sentences and asked to talk about your life and whānau/family. You will also be asked some questions about your memory. These sessions will be video-taped so the researchers can listen to them later.

3. How long will I be in the study?

You will be in 14 to 17 sessions; 1 session for the memory test and the rest of the sessions to talk about your life and whānau/family. Each session will last 5 minutes, five days of the week. Only the first 3 to 4 sessions will be conducted without a memory aid. The last session is a follow-up and will be conducted four weeks after the previous session.

4. Can I stop being in the study?

You may stop being in the study at any time. If you decide to stop participating in the study, there will be no penalty to you, and you will not lose any benefits to which you are otherwise entitled. Your decision will not affect your future relationship with Alzheimer's Canterbury, the Canterbury District Health Board, or The University of Canterbury.

5. What bad things might happen to me if I am in the study?

Nothing bad will happen in this study. But some people get embarrassed when they can't find the word they want to use when talking. If you begin to feel confused, sad, or upset at any time during a conversation with the researcher, the session will stop.

6. What good things might happen to me if I am in the study?

You will be able to talk with someone who is interested to know your life story. You will be helping the researcher to know if looking at pictures and sentences on a small computer are good for other people who have similar difficulties in remembering things.

7. Who can I talk to about the study?

For questions about the study you may contact Katrina Aitken, Speech and Language Therapist on 337 7997, extension 66205; or email Katrina at katrina.aitken@pg.canterbury.ac.nz

To discuss other study-related questions with someone who is not part of the research team, you may contact

8. Will other people see my personal information?

Any information or pictures you provide will remain confidential to this study.



Consent to Participate in Research

Study Title What are the effects of a digital memory book on the quality and quantity of conversations in adults with mild-moderate dementia?

Researcher Katrina A. Aitken

This is a consent form for research participation. Please read and consider the information carefully.

Your participation is voluntary. Feel free to ask questions before making your decision whether or not to participate. If you decide to participate, you will be asked to sign this form and will receive a copy of the form.

- ☐ I have read and I understand the information sheet dated 08/06/2013 version 1 for participants taking part in the study designed to investigate the effect of a digital memory book on conversation.
- ☐ I have had the opportunity to discuss this study.
- ☐ I am satisfied with the answers I have been given.
- ☐ I have had the opportunity to use whānau support or a friend to help me ask questions and understand the study.
- ☐ I understand that taking part in this study is voluntary (my choice), and that I may withdraw from the study at any time, and that this in no way will affect my relationship with

Appendix B – Consent Form for Participants

Alzheimer's Canterbury, the Canterbury District Health Board, or The University of Canterbury.

- ☐ I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.
- ☐ I understand that the session will stop if the participant is identified as being at risk.
- ☐ I have had time to consider whether to take part in this study.
- ☐ I know who to contact if I have any questions or concerns about this about this study in general.
- ☐ I wish to receive a written report about the results – the published results may not be available until July 2015. **Yes/ No**
- ☐ I would like the researcher to discuss the outcomes with me. **Yes/No**

I _____ (*full name of participant*) hereby consent/assent to take part in this study.

Date _____

Signature _____

I _____ (*full name of family member*) hereby consent to take part in this study.

Date _____

Signature _____

Investigator/Research Staff

I have explained the research to the participant or his/her representative before requesting the signature(s) above. There are no blanks in this document. A copy of this form has been given to the participant or his/her representative.

Appendix B – Consent Form for Participants

_____ (*full name of researcher*)

Date _____

Signature _____

If participant is judged unable to provide informed consent, proxy assent will be gained from Enduring Power of Attorney for Care and Welfare.

I _____ (*full name of Enduring Power of Attorney for Care and Welfare*) hereby give consent for _____ (*full name of participant*) to take part in this study.

Date _____

Signature _____



Consent to Participate in Research

Study Title	What are the effects of an electronic memory book on the quality and quantity of conversations in adults with mild-moderate dementia?
Researcher	Katrina A. Aitken, Department of Communication Disorders Katrina.aitken@pg.canterbury.ac.nz
Supervisor	Dr. Tami Howe, Department of Communication Disorders tami.howe@canterbury.ac.nz
Associate Supervisors	Chris Wyles, Department of Communication Disorders, Christine.wyles@canterbury.ac.nz Professor Michelle Bourgeois, Department of Communication Sciences and Disorders, University of South Florida, U.S.A

This is a consent form for research participation. Please read and consider the information carefully.

Your participation is voluntary. Feel free to ask questions before making your decision whether or not to participate. If you decide to participate, you will be asked to sign this form and will receive a copy of the form.

- ☐ I have read and I understand the information sheet for participants taking part in the study designed to investigate the effect of an electronic memory book on conversation.
- ☐ I have had the opportunity to discuss this study.
- ☐ I am satisfied with the answers I have been given.

Appendix C – Consent Form for Family Members

- ☐ I have had the opportunity to use whānau support or a friend to help me ask questions and understand the study.
- ☐ I understand that taking part in this study is voluntary (my choice), and that I may withdraw from the study at any time, and that this in no way will affect my relationship with Alzheimer's Canterbury, the Canterbury District Health Board, or The University of Canterbury.
- ☐ I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.
- ☐ I understand that the session will stop if the participant is identified as being at risk.
- ☐ I have had time to consider whether to take part in this study.
- ☐ I know who to contact if I have any questions or concerns about this about this study in general.
- ☐ Do you wish to receive a written report about the results – the published results may not be available until July 2015. **Yes** ☐ **No** ☐
- ☐ Would you like the researcher to discuss the outcomes with you? **Yes** ☐ **No** ☐

I _____ (*full name of family member participant*) hereby consent/assent to take part in this study.

Date _____

Signature _____

Investigator/Research Staff

I have explained the research to the participant or his/her representative before requesting the signature(s) above. There are no blanks in this document. A copy of this form has been given to the participant or his/her representative.

_____ (*full name of researcher*)

Date _____

Signature _____